Chronic Lyme Disease: A Survey of Connecticut Primary Care Physicians

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**Objective**  To determine how frequently Connecticut primary care physicians are diagnosing and treating patients with chronic Lyme disease.

**Study design**  A survey was mailed to a random 33% sample of primary care physicians in Connecticut, which asked how many cases of Lyme disease and chronic Lyme disease they diagnosed and treated in the last 3 years.

**Results**  The survey had a response rate of 39.1%. Physician respondents (n = 285) fit in one of 3 groups. Group 1 included 6 of 285 (2.1%) physicians who diagnose and treat patients with chronic Lyme disease. Group 2 included 137 of 285 (48.1%) physicians who are undecided on the existence of chronic Lyme disease, but did not diagnose or treat any patients with chronic Lyme disease. Group 3 included 142 of 285 (49.8%) physicians who do not believe in the existence of chronic Lyme disease.

**Conclusion**  A small percentage (2.1%) of primary care physicians diagnose and treat patients for presumed chronic Lyme disease. (J Pediatr 2010;157:1025-9).

The existence of “chronic Lyme disease” has been sharply debated in the last decade. Chronic Lyme disease has been defined by its supporters as persistent *Borrelia burgdorferi* infection requiring months to years of intravenous antibiotic therapy, oral antibiotic therapy, or both. Prolonged antibiotic therapy for presumed chronic Lyme disease is not recommended by the American College of Rheumatology, the American Academy of Pediatrics, the Infectious Diseases Society of America (IDSA), or the American College of Neurology. The IDSA Lyme disease treatment guidelines specifically warn against using intravenous antibiotic therapy for presumed chronic Lyme disease. Opposing the recommendations from these medical societies is a well-organized network of physicians, patients, and patient advocates who, via testimonials, case histories, and other anecdotal forms of evidence, promote the concept of chronic Lyme disease in the medical literature, in the lay literature, and on the Internet. The chronic Lyme disease advocates have started their own society (International Lyme and Associated Diseases Society [ILADS]) and published their own Lyme disease diagnostic and treatment guidelines. These advocacy groups, which refer to themselves as “Lyme literate,” include physicians, patients, and laboratory personnel. Protests have occurred when insurance companies will not pay for prolonged (90-day) courses of intravenous antibiotics prescribed for patients with presumed chronic Lyme disease. As a result, chronic Lyme disease advocates have initiated legislation requiring insurance companies to pay for prolonged intravenous antibiotic therapy (Connecticut House Bill 5625, 2009). An argument put forth by advocates for chronic Lyme disease is that a large number of community-based primary care physicians do not support or follow the academic guidelines of the American Academy of Pediatrics, IDSA, and American College of Neurology. Instead, these community-based physicians commonly diagnose patients with chronic Lyme disease and treat these patients with prolonged courses of intravenous antibiotics, oral antibiotics, or both. The purpose of our study was to survey a random sample of Connecticut primary care physicians to determine whether they diagnose and treat patients with what they believe is chronic Lyme disease.

**Lyme Disease**

Lyme disease is a multisystem infection caused by the spirochete *Borrelia burgdorferi*. The clinical manifestations were initially divided in stages, but now are divided in early localized, early disseminated, and late Lyme disease. Early localized Lyme disease is characterized by the rash erythema migrans (EM). Early disseminated Lyme disease is characterized by multiple erythema migrans, cardiac findings (usually carditis with second- or third-degree heart block), neurologic findings (usually cranial neuritis, lymphocytic meningitis, or motor/sensory radiculoneuritis). Late Lyme disease is characterized by rheumatologic findings (usually arthritis involving the knee) or objective neurological findings (usually neuropathy, encephalitis, or encephalopathy). Lyme disease usually can be treated with 10 to 28 days of a single oral antibiotic. Patients with meningitis, encephalitis, encephalopathy, or carditis may require 14 to 28 days of intravenous antibiotic therapy.
need to have visited an area where Lyme disease is endemic. Patients with objective cardiac, neurologic, or rheumatologic manifestations of Lyme disease should have positive \( B\) burgdorferi serology results. Seropositivity is defined by positive results on enzyme-linked immunosorbent assay and a positive immunoblot test result. Serology may remain positive for years after successful treatment of Lyme disease. Many other unvalidated tests are available (including urine tests) to presumably document acute and chronic \( B\) burgdorferi infection.\(^7,16-18\)

**Connecticut**

In 1977, Steere et al\(^19\) reported a cluster of patients (39 children and 12 adults) with a mysterious arthritis. The patients came from 3 bordering Connecticut communities, Old Lyme, Lyme, and Haddam. The illness was named Lyme arthritis. In the next decade, the mysteries of Lyme arthritis were solved. Lyme disease or *Lyme borreliosis* became recognized as a deer tick-borne multisystem infection caused by the spirochete \( B\) burgdorferi. According to the Centers for Disease Control and Prevention, Connecticut has the highest incidence of Lyme disease in the United States.\(^20,21\)

**Chronic Lyme disease**

Chronic Lyme disease has been defined by ILADS as a chronic debilitating illness with subjective symptoms such as fatigue, arthralgia, myalgia, poor concentration, headaches, and irritability.\(^4\) ILADS states that chronic Lyme disease is caused by persistent infection with \( B\) burgdorferi unresponsive to standard courses of antibiotic therapy. Patients with chronic Lyme disease may or may not have a history of objective findings consistent with Lyme disease, may or may not have positive \( B\) burgdorferi serology results, and may or may not have visited an area where Lyme disease is endemic. According to ILADS, patients with chronic Lyme disease need months to years of treatment with oral antibiotics, intravenous antibiotics, or both (frequently with multiple antibiotics simultaneously). Even after years of treatment, \( B\) burgdorferi infection may persist. Diagnosing and treating chronic Lyme disease is based on the judgment and experience of the treating physician.\(^4\)

**Methods**

A list of physicians who were licensed in Connecticut in 2006 was obtained from the Connecticut Department of Public Health (Health Care Licensing Database). We searched this list for primary care physicians who practiced family medicine, internal medicine, or pediatrics. Physicians from this group who listed a subspecialty or who practiced outside Connecticut were eliminated. Our search yielded 3091 physicians. A 33% sample of the 3091 physicians was chosen randomly with a number generator in Microsoft Excel 2003 (Microsoft Corp., Redmond, Washington). Only one mailing was done in this study. Surveys that were returned did not specifically identify the physician responder. Thus, non-responders could not be sent a second mailing.

A 1.5-page survey (Appendix; available at www.jpeds.com) was mailed to each physician. As background, physicians were told that chronic Lyme disease was a controversial topic and that it is was unknown how frequently primary care physicians diagnosed it and treated patients with chronic Lyme disease. Chronic Lyme disease was defined as persistent \( B\) burgdorferi infection requiring prolonged antibiotic therapy; furthermore, patients with chronic Lyme disease may never have had objective signs consistent with Lyme disease and may be seronegative for \( B\) burgdorferi antibodies.

Physicians were asked whether they were actively practicing family medicine, internal medicine, and/or pediatrics and whether they were practicing a subspecialty. Physicians were then asked to estimate the number of their primary care patients in whom they had diagnosed and treated Lyme disease, chronic Lyme disease, or both in the last 3 years. They were also asked about the length of antibiotic therapy that they prescribed for their patients with Lyme disease and chronic Lyme disease. For chronic Lyme disease, physicians were asked whether they were experienced in diagnosing it and treating patients with chronic Lyme disease, whether they were undecided as to the existence of chronic Lyme disease, or whether they felt that chronic Lyme disease did not exist. At the end of the questionnaire, there was a space for comments.

An average and SD was calculated for the entire data set for the number of Lyme disease and chronic Lyme disease cases diagnosed by each physician. A \( z\) test was done, and outliers 3 SDs from the mean \((z > 3.0)\) were removed from the data set when comparing the number of Lyme cases diagnosed per physician per year in groups. The University of Connecticut institutional review board approved the study. The responders and non-responders could not be identified, and thus non-responders could not be sent a second mailing.

![Figure 1. The practices of Connecticut primary care physicians for chronic Lyme disease.](https://www.jpeds.com)
Results

A total of 1034 surveys were mailed to physicians' offices, and 191 were returned because of outdated or incorrect addresses; thus 843 surveys were successfully mailed. Three hundred thirty responses were received, for a 39.1% (330/843) response rate. Of the 330 surveys, 45 respondents were omitted from this analysis: 10 were from physicians no longer in practice; 2 were not from physicians; 20 were from physicians with a subspecialty; 5 were from physicians who had not diagnosed Lyme disease or chronic Lyme disease in any patients in the last 3 years; and 8 had undecipherable answers.

Of the 285 responses included in the study (Figure 1), 6 were from physicians (2.1%) who diagnosed chronic Lyme disease and treated patients with it (group 1). One hundred thirty-seven physicians (48.1%) were undecided as to the existence of chronic Lyme disease (group 2). One hundred forty-two physicians (49.8%) felt chronic Lyme disease did not exist (group 3). Of the physicians in group 1, 50% were family physicians and 50% were internists; in group 2, 21% were family physicians, 46% were internists, and 28% were pediatricians; in group 3, 17% were family physicians, 33% were internists, and 48% were pediatricians. A few physicians in groups 2 and 3 were emergency or medicine/pediatrics physicians.

In the last 3 years, the 285 physicians in our survey estimated that they had diagnosed 11 970 cases of Lyme disease or 14 cases of Lyme disease per physician per year (outliers included). In addition, 6 physicians estimated that they had diagnosed 84 cases of chronic Lyme disease or 4.7 cases of chronic Lyme disease per physician per year. Histograms depicting the number of cases diagnosed per physician were made for each group and are shown in Figures 2 and 3. The histograms demonstrate outliers in each group. Five outliers (>3 SDs above the mean) were included that diagnosed ≥100 cases of Lyme disease each year: one from group 1, two from group 2, and two from group 3.

The 6 physicians in group 1, who diagnosed chronic Lyme disease and treated patients for it, diagnosed an average of 3.1 cases of chronic Lyme disease per physician per year (when the outlier who diagnosed 40 cases per year was excluded). In addition, they diagnosed an average of 11.5 cases of Lyme disease (not chronic) per physician per year (when the outlier who diagnosed ≥100 cases per year was excluded). Each physician in group 1 diagnosed more cases of Lyme disease than chronic Lyme disease. The average was one case of chronic Lyme disease for every 9 cases of Lyme disease (range, 2.4-18.0 cases of Lyme disease for each case of chronic Lyme disease with outlier included).

The 137 physicians in group 2, who were undecided or did not have an opinion about the existence of chronic Lyme disease, diagnosed an average of 11.4 cases of Lyme disease per physician per year (when the two outliers who diagnosed ≥100 cases per year each were excluded).

The 142 physicians in group 3, who did not believe that chronic Lyme disease exists, diagnosed an average of 12.4 cases of Lyme disease per physician per year (when the two outliers who diagnosed ≥100 cases per year were excluded).

The physicians in groups 1, 2, and 3 treated patients with Lyme disease for 2 to 4 weeks. The physicians in group 1 used an average of 20 weeks (range, 8-52 weeks) of antibiotic therapy to treat patients in whom they diagnosed chronic Lyme disease.

Some of the physicians (159/279) in groups 2 and 3 reported that other physicians had diagnosed chronic Lyme disease in many of their primary care patients. Most
physicians reported that their patients in whom chronic Lyme disease was diagnosed were not helped by the oral and intravenous antibiotics, and sometimes underlying diagnoses, such as depression and in one case leukemia, were missed.

**Discussion**

Our study is a large survey asking primary care physicians about chronic Lyme disease practices. The acceptance or rejection of the concept of chronic Lyme disease has polarized Connecticut physicians. Approximately half (48.1%) of the physicians (group 2) had no opinion about chronic Lyme disease. We found that only 6 of the 285 physicians (2.1%) diagnose chronic Lyme disease and treat patients with it. Five of the 6 physicians treated patients with chronic Lyme disease for <6 months; one physician treated patients with chronic Lyme disease for 12 months. No physician commented that he/she used intravenous antibiotics to treat patients with chronic Lyme disease. Thus, the physicians we identified who diagnose chronic Lyme disease and treat patients with it differ from “Lyme literate” physicians because the “Lyme literate” physicians treat hundreds of patients with chronic Lyme disease each year, with months to years of antibiotics given orally or intravenously. “Lyme literate” physicians did impact our study, because 159 of the 279 physicians in our groups 2 and 3 reported that many of their primary care patients were diagnosed as having chronic Lyme disease by other physicians, and some of these patients were treated with antibiotics intravenously.

The origin of chronic Lyme disease can be traced to the 1989 publication by Burrascano, who described his personal experiences treating 284 patients with Lyme disease. Of the 284 patients, 269 (95%) became chronically infected with B. burgdorferi because they were initially treated with a <60-day course of antibiotics. The initial antibiotic therapies included doxycycline, penicillin V, amoxicillin plus probenecid, or ceftriaxone intravenously. A few years later, Burrascano reported that he was following thousands of patients with chronic Lyme disease who had B. burgdorferi infection resistant to standard therapy. In these early reports, Burrascano did not give a case definition of chronic Lyme disease and did not specifically define the treatment of chronic Lyme disease.

In 1998, Phillips et al reported recovering B. burgdorferi from the blood of 39 of 41 patients (95%) with chronic Lyme disease who were receiving prolonged antibiotic therapy. Most of these patients had seronegative results for B. burgdorferi antibodies and lacked objective findings consistent with Lyme disease. This study by Phillips could not be reproduced, and the culture medium used by these investigators subsequently was shown to be bactericidal for B. burgdorferi.

In the late 1990s, Burrascano, Phillips, and other physicians organized the ILADS society to promote national and international awareness of chronic Lyme disease. ILADS states that chronic Lyme disease is being ignored by mainstream medicine. Physicians and patients who support ILADS have formed a network throughout the United States. This network includes physicians who practice in states where Lyme disease is not endemic (for example, Florida and Colorado). ILADS does not have a clear case definition of chronic Lyme disease or specific treatment recommendations, except that oral/intravenous antibiotic therapy may be needed for months to years.

In 1999, two Connecticut physicians testified at a public hearing that they were diagnosing and treating hundreds of patients each year with chronic Lyme disease. They maintain that treatment of chronic Lyme disease requires months to years of oral and intravenous antibiotic therapy. Later, another Connecticut physician testified that he diagnoses Lyme disease in 999 of every 1000 patients (usually self-referred) that he sees (Connecticut public record, Sep 12, 2008, testimony of Charles Ray Jones, MD). This physician sees mainly children and treats many of them with antibiotics intravenously for chronic Lyme disease.

We know of only a small number of “Lyme literate” physicians from Connecticut and the Northeastern states who diagnose chronic Lyme disease and treat patients with antibiotics intravenously. However, this small number of physicians is influential. The “Lyme literate” network has been pivotal in advocating legislation in multiple states requiring insurance companies to cover the costs of intravenous therapy for presumed chronic Lyme disease. The attorney general of the state of Connecticut, with input from “Lyme literate” network, issued a subpoena to the IDSA claiming unfair trade practices because the IDSA did not acknowledge chronic Lyme disease in their Lyme disease treatment guidelines. Finally, on Apr 30, 2009, the Connecticut House of Representatives passed legislation (HB 6200) that reassured physicians who diagnose chronic Lyme disease and treat it with long-term antibiotics that they will not be subject to any disciplinary actions.

Our study found that approximately 97% of primary care physicians do not diagnose or treat chronic Lyme disease. We understand that although our sample was random, a sampling bias could occur. Physicians who diagnose and treat chronic Lyme disease may not have responded to this survey because we are not part of their network. Or possibly, advocates for chronic Lyme disease may have been more likely to respond so they could be counted. Also, the same could be said of physicians who believe chronic Lyme disease does not exist. We did not have approval from the institutional review board to contact the non-responders, and thus we were unable to define why physicians were non-responders.

Our study, asking physicians to recollect an approximate number of patients diagnosed with Lyme disease in the past 3 years, may be subject to recall bias. In each group studied, there was significant variation in case numbers. The large SD calculated in each group for Lyme disease cases can be attributed to the geographic variation in the frequency of the disease throughout Connecticut.
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References

Please help us (Michael Johnson 4th year University of Connecticut medical student and Henry M. Feder Jr, MD pediatric infectious disease) by filling out this short questionnaire. The diagnosis and treatment of Chronic Lyme Disease has been ever-present in the news. The purpose of this questionnaire is to tabulate the experiences of Connecticut primary care physicians with respect to Lyme disease and Chronic Lyme Disease. For the purpose of this questionnaire, Chronic Lyme Disease is defined as persistent *Borrelia burgdorferi* (the bacterial agent of Lyme disease) infection, despite multiple standard courses of antibiotics. In general, Chronic Lyme Disease has been said to cause symptoms like headache, trouble concentrating, fatigue, myalgias, and/or arthralgias in a patient with or without a history of Lyme disease. Treatment of Chronic Lyme Disease requires weeks, months, or even years of antibiotic therapy. We have sent this questionnaire to a random sample of Family Physicians, Internists, and Pediatricians practicing in Connecticut. We cannot trace who did, or who did not return the questionnaire and, thus, your answers are anonymous. You may skip questions for any reason. Returning the survey implies consent that your response may be used in our study. Your response is greatly appreciated. Thank you.

Michael Johnson, 4th year medical student

1. Are you in clinical practice seeing patients?
   - Yes
   - No

2. What is your specialty?
   - Family Physician
   - Internist
   - Pediatrician
   - Other ________________

3. How would you describe your knowledge of Lyme disease?
   - I know the symptoms and feel comfortable diagnosing it.
   - I know the symptoms but don’t feel comfortable diagnosing it
   - I don’t know the symptoms and don’t feel comfortable diagnosing it.

4. How would you describe your knowledge of Chronic Lyme disease?
   - I know the symptoms and feel comfortable diagnosing it.
   - I know the symptoms but don’t feel comfortable diagnosing it.
   - I don’t know the symptoms and don’t feel comfortable diagnosing it.
   - I don’t believe it exists. (Go to question #6.)

5. In your experience Chronic Lyme disease includes which of the following? (Check all that apply; you may check none, one, or more than one.)
   - Following treatment for Lyme disease, a patient has persistent symptoms like headache, trouble concentrating, fatigue, myalgias, and/or arthralgias. Some of these patients have Chronic Lyme Disease and require prolonged antibiotic therapy.
   - A patient has never previously been diagnosed with Lyme disease but has persistent headache, trouble concentrating, fatigue, myalgias, and/or arthralgias is seropositive for *Borrelia burgdorferi* antibodies. Some of these patients have Chronic Lyme Disease and require prolonged antibiotic therapy.
   - A patient has never previously been diagnosed with Lyme disease but has persistent headache, trouble concentrating, fatigue, myalgias, and/or arthralgias is seronegative for *Borrelia burgdorferi* antibodies. Some of these patients have Chronic Lyme Disease and require prolonged antibiotic therapy.
   - Other - please describe. __________________________________________

Appendix. Lyme disease survey
6. Over the past 3 years, approximately how many patients have you diagnosed and treated with Lyme disease? ________

7. Over the past 3 years, approximately how many patients have you diagnosed and treated with **Chronic Lyme Disease**? ________ (If “0”, please go to question #8.)
   7a. What has been the average total course of antibiotic therapy for these patients with **Chronic Lyme Disease**? ________
   7b. In your opinion, have these patients with **Chronic Lyme Disease** been helped by the antibiotics?  
      □ Yes  □ No  □ I don’t know

8. Over the past 3 years how many of your patients have been diagnosed and treated for **Chronic Lyme Disease** by other physicians? ________
   8a. In your opinion, have these patients diagnosed with **Chronic Lyme Disease** been helped by the antibiotics?  
      □ Yes  □ No  □ I don’t know

9. In your opinion, how frequently does **Chronic Lyme Disease** occur in Connecticut?  
   □ Commonly  □ Uncommonly  □ Never  □ I don’t know

Comments:

*Please return survey in enclosed pre-paid envelope. Thank you for your time.*

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